

**Prepared For: Anna Hurley-Wallace**

 **University of Southampton**

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ANONYMISED

Int[[1]](#footnote-1): Do you have a notification saying it’s recording?

R[[2]](#footnote-2): Yes, it is.

Int: So, just to double check that you're still happy to go ahead with the interview and that you're still happy to be audio recorded for this?

R: Yes.

Int: Great. Some of these questions we will have gone through in the screening, but I’ll go through them again as a warm-up, okay? Could you tell me a bit about your experience of chronic pain that you were talking about before?

R: From sort of my right wrist to my shoulders to my neck and I’ve had it for quite some time now.

Int: What sort of pain is it? How would you describe it?

R: I think it gets worse throughout the day and towards the end of it, I’m in a lot of pain and, when I get home, even right now I’m lying down, I’ve got a hot water bottle underneath my he- neck. Yeah, it gets worse throughout the day, it’s from an ache to an actual pain.

Int: Sorry to hear you're not feeling very well.

R: Oh, it’s quite normal for me.

Int: Okay. How old were you when you first started experiencing these pains that you're getting?

R: I think about three-years now, I think I was 19/20 ish?

Int: Okay. And what was it like when it first started compared to how it is more recently?

R: Looking back at it, I think I had aches rather than pains and now I realise the difference between sort of having an area which just hurts a little to having actual pain.

Int: Okay.

So you said it is affecting your physical abilities, with having to lie down with the hot water bottle and things, is there any other ways that it affects your physical abilities in the day, maybe when you're at work or studying?

R: Yeah, I’m not as efficient or as quick as I could be, so I get slower throughout the day. I think I’m more susceptible to headaches. It’s affecting my concentration sometimes because I’m just … in pain for [inaudible 00:03:09] can’t concentrate as well as I could.

Int: Do you think that kind of affects your academic work? Do you think it has an impact on it?

R: Yes. But I must admit it’s affecting more of my social life and that sort of aspect more I think because I prioritise, you know, other things than my social life.

Int: Okay. Could you tell me a bit more about the impact it’s had on your social life?

R: I won’t socialise with people as much or if I do want to see friends, I’ll try and see if they’ll come over so we can sort of relax and watch a movie, rather than go out, so that I can be you know, in quite a comfortable position if I’ve got any aches, I can apply, you know how you can get those muscle gels?

Int: Hmmm.

R: I’ll try and apply one of those and I know they smell sometimes, you can kind of tell somebody’s been using them. So I try and stay at home as much as possible just so that I don’t have to go to a place where I could be in an uncomfortable position.

Int: Okay. And, so you find yourself asking people to come round rather than going to the shops or out for dinner and things like that?

R: Yeah, I haven’t been out for a meal for a long time, I’d rather eat at, you know, order in because of, I don't know if I’ll be comfortable in the chair or if I’ll feel as comfortable as I could at home and going to the cinema, it would be nice but I know COVID’s a separate thing but generally, I could be, if somebody was, you know how some people can be quite silly, might kick the back of your chair, I just feel things much moreso, more than others, I think I’m just a bit more sensitive in that way.

Int: Okay. Either separately or as a knock-on effect of that, do you think the pain affects your mood and emotions?

R: It does make me wonder have I done something bad to warrant such pain and I just assume that other people have pain too, but then I realise they don’t, which upsets me more.

Int: Hmm, okay.

You mentioned a couple of things in what we were just talking about, about applying the muscle gels and things...

Could you tell me about advice that you’ve had from any doctors or nurses or other healthcare professionals about what to do about your pain?

R: They talk about hot and cold compressions, take anti-inflammatory medicine which I’m doing, stretches, which I try to do but I must admit, I don't know if I’m doing the best. Everyone seems to be quite hesitant to refer anyone for any physio or anything that, they’ve referred me to an x-ray a few times but it was fine. I think I would need more of a, if I could get physiotherapy, I think my doctor’s quite… you know, not keen to refer me for some reason, if I could get something like that, maybe that would help me much more, that would be more practical but I don't think that will happen so I’ve just given up seeing the GP. I might put in a repeat prescription for some naproxen, but I just leave it there.

Int: Okay, so you potentially would quite like physiotherapy but you're not getting the referrals for that. Was it the GP who gave you the stretches to do then?

R: They just printed out something from a hospital trust, I forgot which one, and it was just some generic advice about particular stretches but you know how the aches of pain can be very different, it might be something that I’m doing day to day that I don’t realise, it would be good to know more about it rather than struggle because generally I’m quite fit and healthy and I’m not overweight, I eat generally healthily. But yeah …

Int: How about someone like a psychologist or anyone alternative, have you had any advice from anyone like that?

R: No.

Int: Okay. In the past when you’ve been trying to find out how to deal with these pains that you're getting, who or where have you turned to first?

R: I’ve spoken to pharmacists which are very keen about selling me gels. I’ve thought about maybe going to see a chiropractor or acupuncturist but then I’ve always been so hesitant because I don’t want to do anything that will make it worse. But I would like to look into other sorts of treatment, but I wouldn’t want to do it unless somebody like a healthcare professional or nurse or doctor suggested it because otherwise I would be worried that I would make it even worse, by going to someone privately.

Int: Okay. What about your friends and family, what advice do they give you or what do they say about it?

R: They’re nice. They sort of try and give me a massage if they can or they feel comfortable doing so because that tends to just… relax me but they just think I’m a bit more fragile than others, but I don't know, I haven’t really spoken to them at length, I think they’re just used to me being... a bit zoned out towards the end of the day and in pain.

Int: How has your experience of medication been? How have you found taking medication and what’s your preference for which ones?

R: I’m taking naproxen and I must admit, I think it’s effective but I get concerned that I’m becoming addicted and I’m not actually sorting out the issue of this. I get quite hesitant to take it because of that.

Int: And do you do the kind of hot and cold press or is it more just the gels that you use?

R: Hmmm, I try to use the gels during the day if I’m out and about because I think that’s better but I try not to use it all the time because if you use too much, you can kind of smell a bit different, some people spot it, some people don’t. I do heat compressions now because it’s coming towards winter but during the summer, I was doing more cold.

Int: And that makes sense as well.

R: Hmmm...

Int: Go on, what were you going to say?

R: Yeah, I-I don’t, I know they say you should maybe rotate between them but I can’t do it because otherwise it would just make me feel sick, if I started doing cold compressions during the winter and hot compressions during the summer, I just couldn’t do it, I should rotate and mix it up or something like that.

Int: Yeah. That’s fair enough. A lot of what you’ve already mentioned are things that you do yourself at home to help cope with the pains you're getting.

Is there anything else you can think of that you do yourself to help cope? I’m thinking of other things like exercises or relaxation or mindfulness?

R: I try to remain calm generally, I’ve learned [inaudible 00:11:49] that being calmer has made me feel more relaxed and that’s really helped with my mood, so I try to listen to more peaceful music towards the end of the day, to help sort of chill, as you can say.

 What else do I sometimes do?... I sometimes see if you know, day-to-day things like ironing or anything like that where I’m maybe not in a good position, that I can get someone else to do just so that I can minimise the strain that I’m putting on myself, that’s something I try to do to keep more relaxed, most of the time it works out...

**Int:** **Okay, it’s okay if you can’t remember that’s fine...**

 I sometimes read about the pain and that’s where I saw your thing on some website, I forgot what the website’s called but about chronic pain, sometimes I read about it because sometimes knowing what makes me feel better, that at least it’s not something that I should be really worrying about, it’s quite common.

Int: Let’s talk about that a bit more. Do you think you could tell me a bit more about internet resources you might try and use to find information about the pains you're getting?

R: I must admit, I think I started with actually looking up the medication that the doctor prescribed me, I’d never heard of it before and then I realised that you can buy it over the counter, I think in Feminax, you get 250mg of naproxen, so that made me realise that what I had been given wasn’t that scary, I was quite worried.

 So I approached this particularly from the medication point of view because I was very worried about what I was putting into my body because you know when you're not familiar with something and you’ve been given what you're told is a dose that you can only get on prescription, I think I got 500mg and you can’t get that but I could buy 250mg and take two, but you can’t really buy 500mg on its own.

 So I researched it from there, what the drugs were, I think I’ve researched more about that than the actual chronic pain. I don't know if that’s normal, but I’d rather know what I’m taking and feel more comfortable with taking it.

Int: Yeah. What websites do you go on when you're looking up this kind of information about the medication?

R: I think the government one is called NICE or something like that, that’s the one that tells you, I think that’s the body that decides whether the NHS supplies medication or not and they put particular information about the side-effects that you could have from taking it. I was very cautious that when I take medication, if any side-effects, that I would deal with them straightaway, I haven’t had any thankfully because I’m always worried that if we take something, it will either not help or actually make it worse. So that was a good website.

 I think one of the drug companies, I don't know if it’s Pfizer or someone else, had information about the drug so I read it from there. And then I was checking pharmacies to see how you could get it because you know how it’s a controlled dosage? I found that interesting because if I was given something really strong, I know we would never get morphine or anything like that, but if I was given something strong, I’d be very hesitant to take it but when I saw that you could potentially just get it over the counter, it feels like this chronic pain, it can be managed.

Int: Yeah. And it certainly can be managed. What about the NHS website itself, have you been on there?

R: I do but I just generally think with it, it’s more geared towards people that have actual diagnosed issues, and I don't know if I have a diagnosis or not, I know what my symptoms are and I’d rather not look too much at that website because I think it only tells you you’ve got this or that, no-one’s confirmed anything to me so that’s why I don’t like using it.

Int: Okay. Yeah - that makes sense as well. What about other kind of similar health advice websites like Healthline or WebMD? Do you...

R: I have used WebMD, I remember seeing bits and pieces there, I think that’s a good website, I don’t remember Healthline but I do think that WebMD is good.

Int: But you can’t remember too much about it?

R: I remember when I started getting foot ache a while ago, it gave me some really useful tips and I actually followed them and I haven’t had it since. I think I just was wearing bad shoes or if I… I don't know, I wasn’t stretching my feet or something and when I started taking its advice, I think three, four weeks later, I didn’t have anymore issues, I was quite impressed.

Int: Okay, that’s good.

Do you go on social media looking for information at all or looking for maybe other people who are experiencing the same as you?

R: I don’t, I try to minimise my phone use just because I think it doesn’t relax me most of the time and after I’ve done something, towards the end of the day I just want to relax, I try and do something where I’m not looking at a screen so I’ve been speaking to you, I’ve got my headphones plugged in, that’s why I don't think you could hear me earlier, I’m just lying down, to me it’s quite peaceful or I prefer to watch television, maybe read a book if I feel up to it but I try not to use social media because I think just makes me think… that it conflicts with my ideas of what real life is like.

Int: Okay. So, you’re not really a big fan of social media anyway?

R: No, I’m not. I think it distorts what we think is real and gives us ideas, of life, and how you should live but it’s not really possible, I don’t really social media but there’s a few people in my life that I would like to keep in contact and I do that with them. But I don’t really understand social media, I must admit.

Int: Okay. What about things like YouTube …

R: I like YouTube and WhatsApp but that’s the only social media I really tend to use.

Int: Why do you like You Tube?

R: Just because if I feel like watching something, to watch a video, it’s easy to watch and that’s really it, I don’t watch You Tube personalities but if there was a clip from certain TV shows, it’s just nice for it to be there.

Int: Okay. I’m interested actually because you mentioned earlier about listening to like calming music and things like that.

Do you use online resources to get those audios or do you do that separately?

R: I must admit, most of the calming music that I use, I’ve picked up from movies so I like some of the Inception soundtrack, quite calming and I will just listen to it on YouTube, so it’s just bits and pieces that I’ve picked up on and what I like to watch. It’s just slow and peaceful, it reminds me of interesting parts where I was quite, I was concentrating but I was relaxed and I was enjoying another time. I think all the music that I’ve listened to actually, were soundtracks that were just so relaxing from different parts of different movies.

Int: So, you use YouTube a bit to look up those soundtracks?

R: Yes, I use that quite a bit.

Int: Okay. What about relaxation apps and things like that, do you have any of those?

R: I did use one where you had to write down a journal every day, like bits and pieces... but it didn’t fit naturally into what I wanted to do because I try not to type too much, it can give me a bit of a strain, I put my neck at an odd angle or something like that, so unless I’m lying down, I don’t really want to do that but when I’m lying down, I don’t really want to be staring at a phone. It just didn’t fit into what I could do.

Int: Sorry - I’m getting a bit of background noise there, I can still hear you but just to let you …

R: Sorry, I’m just stretching.

Int: It’s okay, you stretch if you need to stretch, it’s fine.

R: Sorry, I didn’t realise you could pick that up!

Int: It’s absolutely fine. With the strategies that you use at home and to help yourself cope with pain, have you had any problems that you can think of?

R: Any what, sorry?

Int: Any problems with any with strategies you're using to help with the pain, with anything?

R: Because I try and minimise my use of medication just because I feel much better with myself, knowing that I’m not using something that’s manufactured to help with pain. If I’m really in pain, I can take it, like it tends to just work itself out but I try to avoid it so if it worse, if it the worst comes to the worst or it’s worse, I always keep medication with me, whether it’s in my bag or wherever I’m going so I have it at all my friends’ houses just in case I forget.

 I can take some and that’ll help with the pain but I don't know why, I’m very hesitant to be dependent on medication because if I had taken it every single day for maybe you know, three years now, that would make me feel quite dependent on it. I don't think I would get prescribed that much, anyway I don't know how it works. I take it here and there, but if I really am in pain, I will try and take some and I do try and use gels first if I cannot do compressions.

 With the gels, I will use cold gel, you know how you can do the deep freeze one, and the Deep Heat, I try and mix it up with those because gels are quite different than doing compressions.

Int: So maybe some issues with the medication but you kind of try your best to manage it, it sounds like?

R: Yes, I try to avoid medication. But and yet other people will just tell me, “take the medication, you don’t need to use compressions”, but I want to actually treat the issue rather than just… conceal it.

Int: I know you say you don’t use social media too much, but in terms of internet resources that you have used to help you find out about pain, which internet resources have you found the most helpful?

R: I think WebMD, I liked reading from the NICE website, I think that’s what you call it, the NICE NHS, the people who buy the medicine. I think I read an article in The Guardian about chronic pain, that was quite interesting. I think it’s wikiHow is it? Or something like that? Sometimes they give advice of how to deal with pain, like three or four different strategies, I felt that was interesting.

Int: Why is it that you're more drawn to those ones and why do you find those more interesting above other things you’ve seen?

R: I guess they’re part of bodies that I am told that we can trust. I’m not a fan of the Daily Mail or anything like that so I wouldn’t read anything from there. The NICE thing is part of the NHS so… I think it’s a reliable source, or I’m made to think it’s reliable.

Int: Yeah! Is there any internet resources or apps or websites, anything that you’ve come across that you thought was unhelpful and why was that?

R: I didn’t like the meditation apps or the journal, those sort of apps where you have to write down how your day was, I think I used one a while ago which seemed all right but then I just changed phones and I didn’t download it again, where I would rate how much pain I’m in or how my mood is, that was interesting to see because that’s when I started to see the pattern that during lunch, maybe because it’s because I’ve eaten my lunch, I’m feeling better but before lunch, I was in, not in a good mood and after lunch, I’m not in a good mood so it was nice to see that.

 I think on my iPhone, I’ve got the Health app and it tells me how much I walk or how much I’ve walked, or how many steps, that’s always nice to look at and makes me think that I’m not that unhealthy. That’s a good app, I’m thinking about bad apps now, just starting to think about them, I haven’t really downloaded them, sorry.

Int: You said about one of the meditation apps that you had for a bit and you weren’t too keen on, do you remember which one it was?

R: Reflect? Reflectory? I’m sorry, let me double check on my phone, I think I still have it on there … here it is, Reflectly? I didn’t really like it that much.

Int: With regards to looking up things about your pain, do you think your use of the internet, do you think it’s changed from when you were first getting the pains to how you’re using it now, if at all?

R: No.

Int: Okay.

Is there anything else then that you think would be helpful or would have been helpful previously for managing your pain condition, in terms of online resources?

R: I would have liked to if I knew, how before you know I had this pain, how this pain could arrive or anything that I could do to prevent it, I wish there was more about preventing maybe, building muscle strength, I don't know if this is linked to this pain but yeah, and when the pain started, is there any way to prevent it from getting worse.

Int: Right, so something for when you get the very first pain that’s happening and how to stop it progressing?

R: If my GP had said, “[name], download this app, start rating how your pain is, start looking at if there’s anything we could do to, you know, prevent it or minimise it”, if I could do any stretches or if you can maybe even try and take a break from what’s causing potentially the pain for a few days and yeah, I just wish I had, he had given me more guidance at the start, whether it was for an app or online or just… because I’m sure this doesn’t happen over one day and it must have taken me weeks and then it turns to months, it just became worse over time, if there was any way to sort of do stuff, if there was an app that said, if I can pinpoint exactly where my ache was so they can tell me the best way to stretch it and maybe having [inaudible 00:30:43] any prompts throughout the day, that would be amazing, I think. I don't know if there’s such a thing out there.

Int: No, not specifically. Yes, that’s interesting to hear you say about that in sort of a ‘preventing it from becoming long term’ isn’t it, that you're kind of thinking about there?

R: Yeah, I think even if it was prevention or even long term, I think some of the strategies would overlap a lot so even now, if somebody told me “to minimise your pain, if you do these stretches every day”, I’m pretty sure that’d be part of the prevent things that you should be doing too, it just would be nice to know these more because everyone talks about things like do some strengthening activities like yoga or Pilates but when you're in pain, you don’t feel like doing that so if there’s particular key aspects you could just do at home, or try to do or build up to without having the pressure of anyone else looking at you or another [inaudible 00:31:49], I think you're more likely to do it.

Int: So, you think those things like the yoga and exercises would have been maybe easier to do at the start, before it escalated?

R: I think it would have had more of an impact then but I think even now, I’m thinking about doing stuff like that soon because I haven’t tried to or haven’t fully given it a go, I think it’s important when you're in pain, to try and see if there’s any way that you can minimise it through not taking medication so try to do strengthening activities or something like that. I don't know if it will help but I definitely am going to do it soon. I probably will give up quite quickly, knowing me though.

Int: Start and try and the main thing is starting something first and then seeing …

R: I imagine doing it, me being in a little bit more pain and thinking I’m making it worse, it just one of those little dips before things get better. I think that’s why it’s always better to do things like exercise earlier on when you’ve got pain because otherwise, afterwards when you start stretching, it’s in areas which it’s going to make it worse and then you don’t want to do it. You don’t want to be in further pain, do you? And that’s why I am very apprehensive when I do exercise.

Int: Okay, and that makes sense completely what you're saying as well.

Do you have anything else to add to anything that we’ve talked about so far? Or add to anything that you've said already?

R: No, but I do think chronic pain for people, you know, that are going to be the next generation, I’ve seen kids these days, it’s only going to get worse because I don’t have any weight-related issues but some people do, I think that just makes everything more difficult and that’s, I mean I’m struggling with this pain now, and thankfully everything else in terms of my health is okay, I don’t have any blood pressure issues, I don’t have any weight issues but I just don't know how somebody else with other issues would manage with pain, you know?

**Int: Yeah, I understand that, yeah.**

R: That’s what I’m worried about, if I had diabetes or if I had blood pressure or if I had issues with my knees because of my weight or something like that, that would be the worst thing.

 Can I ask, what are you going to do with all this information again?

Int: I’ll just close the interview up and then I’ll go through that with you.

R: Sorry, I’m a bit curious.

Int: That’s okay, that’s the end of my questions, what I’ll do is I’ll turn off the recording and then we can talk about questions you’ve got for me, okay?

R: Great, thank you.

[CLOSE]

1. Interviewer [↑](#footnote-ref-1)
2. Respondent [↑](#footnote-ref-2)